BPSD project qualitative data – supplementary tables

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Table 4: Overview of study characteristics from qualitative studies (51 studies, 53 papers)

pwd=people with dementia

Study Information	Study Methods	Types of Participants
Year of information Range : Jan 2000 – Dec 2014 **Impact of papers on objectives BPSD** Very good: n=17 Good: n=7 Fair: 9 Low: n= n=2 Very low: n= 18 **Country:** • UK n=21 • Europe n= 7 • USA n=6 • Australia n=6 • China n=5 • Canada n=3 • India n=1 • Tanzania n=1 • USA & Canada n=1 **Setting** (studies may be classified more than once) • Home/Community n=51 (e.g. day hospital, activity centre, respite centre, health centre, memory clinic)	**Data collection methods** Interviews: n=28 FG: n=12 Mix Interview & FG: n=6 Mix Interview & Diary/notes n=2 Mix Interview & Observation n=1 Written Comments n=2 **Methodology / Analysis** • Grounded theory n=11 • Phenomenological n=10 • General Thematic analysis n=9 • General Content analysis=3 • Other n=5 (double hermeneutic approach, information synthesis, inductive comparative analysis) • Not specified n=12 **Recruitment** (studies may be classified more than once) • Community services n=20 (e.g. day centre, Café, activity centre, support group • Health Care services n=17 • Alzheimer Society/Association n=5 • Memory Clinic n=4 • Hospital/Day hospital =4 • Not reported n=4 **Sample**	**Participants** • Carer n=35 • Pwd n=2 • SP n=2 • Carer & pwd n=8 • Carer, pwd & SP n=3 • Carer & SP n=1 **Age** • Carer: range 18 – 95 mean 62.8 (based on 23 reported studies) • Pwd: range 51 – 98 mean 76.7 (based on 18 reported studies) **Ethnicity** (studies may be classified more than once) • Black n=2 • African-Caribbean n=1 • White British =1 • Caucasian n=1 • African-American n=1 • Asian n=6 • Hispanic white n=1 • White non-Hispanic n=1 • not reported n=36

Relationship to carer (studies may be classified more than once) • Lived with Spouse/Partner n=37 • Lived with child/child in-law n=25 • Siblings n=4 • Other n=8 (alone, widow, not reported) **Stage of dementia** (studies may be classified more than once) • Early/mild n=13 • Moderate n=14 • Sever n=5 • Not reported n=29	• Purposive n=17 • Convenient =3 • Part of larger study =7 • Not clear n=15 • Not reported n=9 **Number of data collection points** • Once n=43 • Twice or more n=8 **Type of Dementia** (studies may be classified more than once) • Alzheimer's: 13 • Dementia n=31 • Vascular Dementia n=5 • Other n=5 (e.g. Front temporal dementia, Lewy body, mixed, fvFTD) • Not reported n=3	**Types of BPSD (**studies may be classified more than once) • Risky n=14 • Embarrassing-strange n=13 • Aggression-anger-violence n=11 • Repetitiveness n=7 • Wandering n=7 • Anxiety, fear n6 • Agitations n=6 • Hallucinations n=6 • General behavioural changes n=10 • Other e.g. (confusion, Irritable, depression, obstinacy, distress, apathy, frustration, passive behaviours, withdrawal, mood swings, nocturnal disturbances)

Table 5: Characteristics of included qualitative studies (53 papers, 51 studies)

Author Year Country	Recruited from	N of sample Perspective	Age	Data collection methods	Aim of Paper	Methodology Analysis	Weight reliability	Weight usefulness
Au 2013 Hong Kong	Day-care centre for people with dementia and psychogeriatric unit of a general hospital.	Carer=11	Carer: mean 58 Pwd: mean 82	Semi structured interviews	to explore the possible differences between the coping mechanisms and help-seeking behaviours deployed by Western and Chinese people	identify recurrent themes	high	high
Bruce 2000 Australia	Live-in carers of dementia user who had been seen by members of the Fremantle ACAT	carer=24	carers mean age 69 pwd mean age 79	semi structured interviews	to study the impact of the Age Care Assessment Team ACAT	categories were systematically compared	medium	medium
Camic 2013 UK	Recruited from an older people's community mental health service in England	pwd=10 carer=10	pwd: 75 (68-88) carer not given	Semi structured interviews	to determine if participation in a community singing group had a positive impact on both people with a dementia (PWD) and their carers	TA	high	medium
Capus 2005 UK	Kingston Dementia Café	carer=6	not reported	focus group	to determine the usefulness of the Kingston Dementia Café	not reported	low	high
Chan 2010 Hong Kong	from the Community Rehabilitation Network (CRN) of the Hong Kong Society for Rehabilitation	carer=27	range from 36 to 82, median 52	group discussions	to assess the experience and needs of such local carers and suggest appropriate interventional strategies	Phenomenology approach.	medium	high
Colling 2004 USA	not reported	carer=50	pwd 34–92 years of age with a mean age of 76.96 . Carers - ranging from 39–92 years of age with a mean age of 63.77	semi structured interviews	to elicit caregivers' description of passive behaviour	Need-driven Dementia-compromise gunnd Behavior (NDB) Model - framework for study.	medium	high
de la Cuesta-Benjumea 2010	Via healthcare professionals in primary healthcare centres.	carer=22	CG; 40-50: 4. 51-60: 12. 61-70: 3. 70+: 3.	semi structured interviews	to identify the conditions that favour the relief of the burden of women caregivers	GT	medium	low

Spain						Symbolic interactionism		
Ducharme 2013 Canada	Alzheimer Society, or in a day care center.	carer=12	Carer mean55 pwd mean 60	interviews	to document the lived experience of spouse caregivers of young patients	phenomenological TA	high	high
Egdell 2012 UK	Through 58 voluntary sector organizations, community organizations, and support groups operating in the study areas or at a citywide level.	carer=13	carer=in their 70s or older, one in 40s and four in 50s.	interview, diary	to identify the complex routes through support taken by informal caregivers for pwd in the development of their care networks.	GT Connections between the themes were made	high	medium
Farran 2003 USA	from Rush Alzheimer's Disease Center, adult day care centers, senior service organisations and HCP	carer=177 (272 in parent study)	carer mean age 63, pwd mean age 79.	typed group facilitator comments	To addresses content and skills needed by CGs for responding to care recipient (CR) issues.	qualitative content analysis		high
Farran 2004b USA	from Rush Alzheimer's Disease Center, adult day care centers, senior service organisations and HCP	carer=177 68% of all participants	carer mean age 63, pwd mean age 79.	typed group facilitator comments	Describe family CG issues and concerns about care giving.	qualitative content analysis		high
Forbes 2012 Canada	Rural dementia care networks	pwdn=5 carer=14 HPs=14	pwd 77 (63-95), CP 60 (39-91), HCP 46 (24-63)	interview	to enable HCPs, care partners, and PWD to use dementia care information more effectively	A qualitative interpretive descriptive approach TA	high	medium
Gorska 2013 UK	A range of health and social care services by local authority and voluntary sector in Midlothian, Scotland.	pwd=12, Unpaid carers=19	pwd=84 (77-93), carer=65 (40-84)	interviews	To develop deeper understanding of live experience of pwd regarding their service related needs	constant comparative method TA	high	high

Hamill 2012 UK	Through referrals from within the Mental Health Care of Older People's service.	pwd=7, carer=3	pwd=80 (75-84), carer=77 (63-88)	interview, observation	to explore the effects of a circle dance group therapy on pwd and their carers.	self reported observations and weekly monitoring notes	low	low
Ivey 2013 USA	community-based organizations that provide services to older adults and/or caregivers	9FG=carer=75	carer mean=59	FG	to examine daily life experiences of informal caregivers to pwd, and explore how experiences and concerns may differ by ethnicity.	phenomenological process, TA	high	high
Landmark 2013 Norway	Municipal home care district in a medium-sized city in southeast Norway	carers=10	carer=mean=54 (38-63) cared for 2man (m=78 (74-83), female=m=81 (74-83)	FG	to explore and describe relatives' experiences of people with dementia living at home and to reveal the relatives' needs for support.	qualitative content analysis explorative and descriptive	medium	high
Lindqvist 2013 Sweden	Memory clinic, Alzheimer's association	Pwd=12	Pwd mean=66	interview	To describe how pwd with early stage AD became users of Assistant Technology	GT Constant comparative approach	medium	medium
MacPherson 2009 Australia	Through the local Alzheimer's Association.	Pwd=7 Carer=?	Community pwd 70.8 (56-80)	focus groups	to determine whether participants could significantly engage in an activity	GT	high	medium
Marshall 2005 Not reported	not reported	Pwd=9 Carer=?	Pwd 58-81	transcript analysis, interviews	evaluate a 24 week support group for people with recently diagnosed dementia	not reported	low	medium
McHugh 2012 Ireland	Technology Research for Independent Living centre and the memory clinic, both at St James's Memorial Hospital, Dublin	carer=14	Carer 54-82	interviews	to understand the problems experienced by carers, focusing on the spouse or partner living with the pwd.	GT	low	medium
Meiland 2005 Netherlands	(Regional Care Network, Association of Netherlands Municipalities, Alzheimer Netherlands Foundation).	SP=23	not reported	semi-structured interviews & Document analysis	to trace facilitating and impeding factors in the implementation of thirteen meeting centres for pwd and carers.	a theoretical model was developed to guide data	medium	medium

						collection and analysis.		
Moore 2013 Australia	Clinician, agencies	carer=25	Carer mean 56 (36-83, pwd:mean 80 (51-94)	intervew	To investigate how family carers respond to BPSD	information synthesize	high	high
Malthouse 2013 UK	From one memory clinic in South West England.	pwd=5. carer=5	all=64-84	interviews	to gain insight into perceptions about the importance of physical activity; and to understand potential	TA	medium	medium
McCabe 2013 UK	A support group for younger people with dementia in Scotland and a day centre for pwd from BME in England	pwd=12, carer=3	all participants over 60y	FG	to explore the ideas and opinions of potential users about a GPS device	TA	medium	medium
Mushi 2014 Tanzania	From the Hai District of Kilimanjaro.	pwd=25, carer=16	pwd=84, carer=19-58	interview	explored the socio-cultural beliefs surrounding dementia and the life experience of pwd and their caregivers	content analysis approach	high	medium
McDermott 2014 UK	OM's professional network.(lead researcher Orii McDermott)	pwd=4, carer=? therapists=8	not reported	interview, FG	to develop further insights into the musical experiences of pwd and explore the meaning of music in their lives.	general inductive approach similar to GT Systematic analysis	high	high
Mahoney 2013 USA	Aggressive multi-pronged community outreach campaign, using newspaper and online advertisements, presentations and brochure mailings to Alzheimer's support groups and geriatric clinics.	carer=25	carer: mean=63 (39-83)	FG/ Interview	to increase understanding of Alzheimer's family caregivers' experiences with dementia-related dressing issues	GT constant comparative. explorative and descriptive	high	high

Martin 2013 UK	Social work teams and medical staff from a local large mental health institution.	pwd=8, carer=? HP=?	not reported	interview	to explore NOCTURNAL technology to offer therapeutic intervention to pwd and carers	Phenomenological	medium	medium
Melunsky 2013 UK	RYCT or combined CSP-RYCT intervention as part of the SHIELD-CSP trial	carer=18	carer: mean=67 (41-85)	interview	an evaluation of the RYCT approach	Phenomenological explorative inductive (bottom-up) TA	high	medium
Milne 2013 UK	Medway Memory Service	carer=73	not reported	written comments	Evaluation of the Carers Course	grounded TA	medium	medium
Nichols 2013 USA & Canada	TWC (author) was the treating physician for the parents of some participants.	carer=14	carer=11-18	fg	To learn more about the needs and experiences of young carers for pwd in order to create a relevant support website	TA	medium	medium
Oyebode 2013 UK	Through clinical staff at two specialist, working-age-dementia services	carer=6	not reported	interview	to explore how relatives of pwd experience the illness and how it impacts their lives.	IPA idiographic	high	high
Paton 2004 UK	Through mental health teams in the participating trusts	formal and informal carers=205	28–93 years (mean=63 years). Pwd 55–98 (mean 81 years)	interviews	To explore how CG describe difficult symptoms displayed by the pwd	not reported	low	high
Perraud 2004 USA	From Rush Alzheimer's Disease Center, adult day care centers, senior service organisations and HCP	Carers= 177, 68% of all participants	carer mean age 63, pwd mean age 79.	typed group facilitator comments	to identify issues arising from the group processes that could be used to inform future skill-building caregiver groups	qualitative content analysis	medium	low
Phillipson 2012 Australia	Via letter through an agency coordinating the local branch of a national respite helpline	Carers =36	mean 71	semi structured interviews and focus groups	identifying beliefs informing day center use and whether these beliefs differ for service users and nonusers	theory of reasoned action and the theory of planned behaviour	medium	high

Powell 2010 UK	Most participants were recruited with the help of community psychiatric nurses employed by NHS community mental health teams and of the group leaders of user and carer voluntary organisations.	carers 4 ints, 9 FG	age range 20–99, most (29) between 40-79	interviews and focus group	to investigate the perspectives of carers of pwd about new networked technologies.	framework approach This is a grounded method	medium	medium
Quinn 2013 UK	From the caseloads of Admiral Nurses (specialist mental health nurses for caregivers of people with dementia) based in the North-West of England.	carer=12	carer:mean=65 (41-88), pwd mean=76	interview	to explore how meaning, motivation and relationship dynamics influence the caregivers' experience of caregiving.	IPA Thematic account decontextualisation	high	high
Robinson 2012 Australia	Via health services/professionals such as general practitioners (GPs) and HACC but who did not all accept the offer of this service.	carer=27	carer:mean=78 (appx30-95)	telephone interviews	to identify issues around the use of day respite care from the perspective of the family carer,	not reported constant comparative analysis	high	medium
Salfi 2005 Canada	Alzheimer Society & multiservice agency	Carer =10 HP=?	carer: 50 - 80, pwd: 70 - 90	Interview & notes	to explore the intervention of telephone support for care-givers.	categorical aggregation	medium	medium
Samia 2012 USA	not reported	carer=26	carer: less than 60 to 84	fg	to explore the ongoing learning needs and preferences of previously trained caregivers.	content analysis constant comparative analysis	high	high
Soderhamn 2013 Norway	Activity center were informed about the study by the professionals in the center, in connection with	carer=10	carer:mean=66 (36-83)	FG	to elucidate the experiences of next of kin to pwd who participated in physical and social activities.	content analysis	medium	medium

	an information meeting and group meetings							
Stokes 2014 UK	Through a local dementia support group	carer=7	not reported	interview	to explore how caring partners understand and make sense of diagnostic information.	IPA grounded	high	high
Sun 2013 China	The largest mental health center in Shanghai was selected for participant recruitment.	carer=18	carer:Mean=65 (53-82)	interviews	to identify caregiving stressors and coping strategies in family CG and pwd	conventional and directed coding TA	high	medium
Scott 2005 UK	They were selected from caseloads (community psychiatric nurse) and admissions to the wards.	Carer=7	not reported	focus group	to develop an understanding of challenging behaviour and how it impacted on the lived of family caregivers.	not reported	medium	high
Shaji 2003 India	not reported	Carer=17	not reported	unstructured interviews	to obtain information on the range of care arrangements, attitudes towards care giving roles and sources of strain	not reported	medium	high
Sorensen 2008 Denemark	A sub-sample of 11 couples of patients and their caregivers out of 165 couples randomised to the intervention in the Danish Alzheimer Intervention Study	pwd and carer n/a	pwd range 65-81, carer range 65-85	semi structured interviews	to identify the personal experience of patients and their caregivers about a social intervention programme on coping with everyday life	a template organizing style of interpretation	low	medium
Tott 2013 UK	Voluntary sector organizations such as dementia uk and local carer support groups	carer=15, pwd=18, HP=19	pwd<65, 17>65, carer 6<65, 9 >65	FG	to identify which factors may lead to crisis for pwd and their carers and identify interventions	Inductive comparative analysis TA	high	high
Vernooij-Dassen 2010 USA	Counsellors who delivered the int	Counsellors=3	mid 60s - 95	group interviews	to gain insight into the actual provision of effective family counselling in the context of caring for a relative with AD	not reported	medium	medium

Vaingankar 2013 China	From three tertiary hospitals and health carer employees, welfare organizations.	carer=63	carer: mean=53, pwd=54-93	interviews, FG	to explore the experiences and challenges of informal caregivers	TA	high	medium
White 2010 UK	From a single commercial provider. The users had either bought the device through the website or availed themselves of a free trial offered by the service provider.	Carer=10	carer: 48 years and partner carer group: 67 years	interviews	to elicit a description of GPS tracking use in the care of people with dementia	GT	medium	medium
Wang 2013 China	Via geriatric clinics in the three large university-associated teaching hospitals in China.	carer=23	carer=45-93 (mean,<60=49, mean>60=72, pwd:mean79 (59-100)	interview	To examine socially, culturally and politically constructed factors affecting family caregiver practice in dementia care	A ‘double hermeneutic approach constant comparative analysis	high	high
White 2014 UK	Through a GPS tracking service provider.	carer=10	not reported	interview	to examine ethical issues associated with use of gps in a domestic setting.	GT	medium	medium
Xiao 2013 Australia	Various community organisations	carer=46	carer=18-85, pwd=72-94	interview, FG	to explore the experiences of family caregivers from Chinese, Greek, Italian and Vietnamese groups in utilising dementia services.	philosophical hermeneutics , phenomenon interpretive TA	high	high

Table 6A : Very good to good qualitative papers (n=24) (contextually rich, good amount of quotations about BPSD)

Au et al 2013; Capus 2005; Chan et al 2010; Colling 2004; Ducharme et al 2013; Farran et al 2003; Farran et al 2004b; Gorska et al 2013; Ivey et al 2013; Landmark et al 2013; Mahoney et al 2013; McDermott et al 2014; Moore et al 2013b; Oyebode et al 2013; Paton et al 2004; Phillipson 2012; Quinn et al 2013; Samia et al 2012; Scott et al 2005; Shaji et al 2003; Stokes et al 2014; Toot et al 2013; Wang et al 2013; Xiao et al 2013

Theme 1: Effect of BPSD/dementia on carer • Impact on relationship (daily activities) • Stress, distress, fed up • Burden on family • Unable to cope • Isolation • Frustration, • Embarrassed • Blame, guild, fear **Theme 2: Types of BPSD experienced by pwd** • Aggression, anger, violence • Passive behaviours • Risky strange embarrassing behaviour • Trajectory-decline - Personality change • Repetitiveness • Irritable behaviour **Theme 3: Barriers to services** • Service not available • Service not helpful • Lack of right information • Family give limited help • GP unaware of services	**Theme 4A: Support Resources pwd** • Physical and structured ○ Music-singing ○ Shared activities ○ Hobbies ○ Occupational therapy • Day Centre/Activity centre • Home Care services • Supportive technology • Counselling (managing emotions) **Theme 4B: Support –Resources carer** • Educational support (greater understanding) • Respite • Family support • Dementia café • Carer network group **Theme 5: Diagnosis / Recognition** • Confusion about diagnosis / wrong diagnosis • Denial of diagnosis (stigma) • Long quest of diagnosis • Recognition of BPSD (not always clear whether dementia or BPSD)	**Summary** It became clear from the data that some BPSD had greater impact on carers and pwd than others, leading to feelings such as stress, distress, isolation or embarrassment. These symptoms often affected the relationship with the partner and other family members. Most importantly, increasing aggression was mentioned by carers as the breaking point where they needed help or were overwhelmed by the demand of coping with such behaviour. Carers would often wait until desperate before seeking external support, first by family members and then by local services. We identified 15 different interventions so far, although some of them are overlapping and need further refinement. Carers mentioned that educational support helped them to learn more about the illness and apply new coping strategies or just sharing their experience with other carers in network groups. However, carers also pointed out that they did not always get the right information because GPs were unaware of services or did not signpost effectively.

Table 6B: Fair to low qualitative papers (n=29) Contextually moderate, reasonable amount of quotations about BPSD (see reference list)

Theme 1A: Support-Resources Carer	**Theme 4: Types of BPSD**	**Summary**

• Assistive technologies, eg GPS (safety) • Carer network support group • Counselling (Managing emotions) • Respite general • Coping strategies-skills **Theme 2: Effect of BPSD-dementia on carer** • Emotional impact • Stress, distressed, fed up • Embarrassed • Isolation • Taking on tasks of daily living **Theme 3: Barriers to services** • Service access problems • Lack of information • Family gives limited help	• Anxiety-fear-worry • Risky, strange, • Personality change **Theme 5: Support resources pwd** • Assistive technology • Reminiscence- RCT • Respite • Support groups **Theme 6: Diagnosis/Recognition** • Receiving diagnosis is helpful (relief) • Confusion about diagnosis • Stigma	Generally the papers support the themes and findings from the 24 high contextually rich papers, such as recognition of BPSD, the impact of BPSD on carers (particularly emotional distress) and people with dementia, the strategies / interventions and barriers to services. There was more emphasis on support resources for carers, such as GPS, carer network groups or counselling. These helped to improve coping skills to manage dementia, including some BPSD symptoms, such as anxiety and risky behaviour. Support resources for people with dementia highlighted were reminiscence and support groups, which generally improved the mood of patients.

Table 7C: UK contextually rich papers (9 papers) (see reference list)

Theme 1: Effect of BPSD on carer	**Theme 3: Barriers to services**	**Summary**

• Impact on relationship (taking on tasks of daily activities) • Isolation • Diminished social live • Embarrassed • Stress • Uncertain future • Frustration • Unable to cope **Theme 2: Types of BPSD** • Risky strange behaviour • Aggression • Repetitiveness, • Hallucination • Anxiety • Confusion	• Lack of information • Unaware of services • Unable to use community carer • Carer delay seeking help until desperate **Theme 4: Diagnosis/Recognition** • Lack of timely information about symptoms • Long quest for diagnosis of BPSD • Despite diagnosis of dementia no support given for BPSD **Theme 5: Support resources** • Carer: music singing, relaxation, educational support • Pwd: music, singing, relaxation	The effect of BPSD on carers was a very prominent theme in the UK based papers, such as impact of BPSD on the relationship in terms of losing a partner (becoming like a child), or taking on tasks that were shared before the onset of BPSD (e.g. finances, shopping). It also affected the social life as the carer needed to be available 24 hours. This brought frustration and stress. Some of the interventions mentioned was singing, which helped the carer and pwd to relax and have social contact with similar people.

Table 7A: Characteristics of people with dementia (End of Study interviews)

ID	Age	Sex	Marital Status	Ethnicity	Who is carer	Date of Diagnosis	Diagnosis	Stage	Co-morbidity	Medication

1	78	male	married	White British	wife	24/02/2012	Alzheimer’s dementia	Mild	Nil documented	Donepezil 10 mg
2	74	female	married	White British	husband	25/04/2014	Alzheimer’s dementia	Moderate	Depression	Citalopram; Rivastigmine
3	77	female	married	White British	husband	03/07/2013	Alzheimer’s dementia	Moderate	Nil documented	Donepezil
4	80	male	married	White British	wife	2012	Alzheimer’s dementia	Moderate	Nil documented	Risperidone
5	67	male	married	White British	wife	07/02/2013	Alzheimer’s dementia	Mild	Nil documented	Donepezil
6	75	male	married	Scottish	wife	21/03/2013	Alzheimer’s dementia	Mild	Nil documented	Donepezil
7	77	male	married	White British	wife	07/01/2014	Alzheimer’s dementia	Mild	Nil documented	Donepezil

Table 7B Characteristics of carers (End of study Focus Group)

	Carer	Person with Dementia

ID	Age Carer	Sex	Relationship to pwd	How long carer	Live with pwd?	Age	Sex	Ethnicity	Marital status	Date of diagnosis	Does pwd lives alone?
1	74	female	partner	3 years	no	73	male	Scottish	Legal separation	2002	Yes sheltered housing
2	69	female	wife	15 years	yes	70	male	White Caucasian	husband	5 years ago	no
3	61	female	wife	2 years	Not since Sept 24th 2014	56	male	Jamaican	separated	Sept 2012	Yes, lives in camper van
4	76	female	wife (widow)	40 years (variously)	No, died 2/11/12	92	male	White British	married	Dec 2004	died
5	78	male	husband	3 years	no	77	female	White British	married	1971	No care home
6	82	male	husband	8 years	No, in carer since 2013	81	female	Welsh	married	2011	In care
7	69	female	wife	-	yes	73	male	-	married	-	No, lives with wife

Table 7C Characteristics of BME carers & pwd (5 interviews of which 3 interviews were carer proxy reports of pwd and 2 carer interviews)

	Carer				Person with Dementia				
ID	**Sex**	**Relationship to pwd**	**How long carer**	**Live with pwd?**	**Age**	**Sex**	**Ethnicity**	**Marital status**	**Date of diagnosis**
1	female	wife	6 years	yes	76	male	Sikh	married	6 years ago
2	female	daughter	2 years	yes	79	male	Sri Lankan	married	2 years ago
3	male	nephew	about 10 years	yes (partly)	87	male	India	divorced	03/02/2014

Table 7D: Characteristics of service providers / health professionals / Commissioners (24 participants in 5 focus groups – 5 participants attended two focus groups)

ID	Job Title, specific area of work, organisation

1	IOT, (RWR) Herts Partnership
2	Support worker
3	Memory nurse, EMDASS, HPFT
4	Occupational therapist, EMDASS, HPFT
5	Memory nurse , EMDASS, HPFT
6	Community lead, community mental health team for older people, HPFT
7	Consultant Clinical Psychologist & Neuropsychologist, HPFT
8	Senior Occupational Therapist, HPFT
9	Herts parts social work
10	Specialty doctor in old age psychiatry, HPFT
11	Senior commissioning manager, hcc
12	Social worker hpft
13	Assistant psychologist, HPFT
14	Commissioning Manager, Integrated Health and Care Commissioning Team
15	GP, East & North Herts
16	Carer Development, Quality & Safety Directorate (Equality & Diversity Team) Hertfordshire Partnership NHS Foundation Trust
17	Dementia Support Manager for the Alzheimer's Society
18	Senior Support Worker Specialist Mental Health Team for Older People North Herts and Stevenage
19	Consultant Psychiatrist

Table 7E: Main themes - Health Professionals/Service Providers Focus Groups (based on 5 focus groups n=24) (Themes and Nodes compared by number of coding references -first theme most prominent)

Theme 1: Service recommendations	**Theme 3A: Support, Interventions & management**	**Summary**

• Some carers need more support – some need more information but both should be individually tailored • Dementia support services need to be resourced so that they are more widely available to improve coping • Flexible respite arrangements as BPSD can change quickly (fast track) • GPs need information about local community services • information for specific BME groups needed • Mapping out dementia care pathways for individual needs with information and training • More information needed about the use of post EMDASS services for carers • Recognition of dementia using 52 different codes by GP • Support needed such as Singing for the brain if the evidence that this works becomes available • Support pathway are in sometimes in place but patients don't know • Service integration and “joining things up” is required but at the level of real support and not rhetoric . • All care and support needs to be flexible • Services are needed to provide help with BPSD ○ Single point of access (lasting from once per week to once per month) ○ 6 week window to see pwd ○ Risk assessment ○ Follow NICE guidelines • Prepare support for carers	• Impact of interventions- massage, pet therapy, music, singing, etc carer may benefit from is unproven, but carers often do not have easy or timely access to post memory services education, psychology, counselling, etc (but matches in someway with pdfs) • Challenges for BME groups • Follow up after memory clinic- carers say nothing given to them at this point so primary care remains the main source of information • Understanding and managing BPSD- some carers need help to learn and understand that the behaviour is not on purpose – would help them cope • Triangle of care- triad of relationship- *may be suitable for some service models* • Carer champions in GP surgery may be worth evaluating **Theme 3B: Additional Interventions or strategies which are needed** • carer education in managing BPSD • carer needs to feel they're not alone • counselling for carer at time of diagnosis • crisis support needs to be available 24 hours (out of hours access to GPs, care and flexible respite) • designated service to report and find information on managing BPSD for each patient • educating GPs with dementia specific training (especially recognition of BPSD) • greater commissioning of day care • interventions that improve mood and address depression for	Recommendations included Involvement of carers (triangle of care document) at all aspects to form a triad of relationships and better interactions. Importance of addressing the barriers to follow up post memory clinic, services and interventions. Some care is integrated but most is fragmented. We need to fund integrated yet individualised pathways to meet the specific needs of pwd and their carers so that we can fill the gaps that are identified from the research. Dementia care pathways toned to be tailored to individual needs. These pathways are meant to map out special dementia information and training. Some support pathways are in place but patients and carers seem not to know about them as may be the case for limited numbers of practitioners. Service co-ordination needs to be more consistent. A Dementia Strategy implementation group may help to initiate integration and joining up with other services in localities.

○ More understanding ○ Help carers with following instructions ○ Empower not deskill carers ○ Strategies around dressing • Services extended to help with BPSD ○ Increase resources ○ Increase referrals ○ Special services for BPSD needed ○ Psychoeducation services • Prepare pwd ○ EMDASS ○ Info at diagnosis or when wanted ○ Monitor for BPSD in follow up ○ Difficulties to talk about future symptoms **Theme 2: Barriers to services** • Financial constraints on services • Not enough training for practitioners in dementia • Carer reluctance to get help • Difficulty getting the patient to GPs • Family carers not willing or able to implement strategies- because carers deny or unable to recognise the condition • Patient and/or carer not accepting the service	pwd and carers • talking through strategies with pwd and family carers together (triad) • Time limited services (- not in pdf • Person centred care **– not in pdf directly, but indirectly** **Theme 4: Recognition of problems** • Challenges recognising and diagnosing BPSD- pdfs mention BPSD in context but not around diagnosis • Knowledge and information of and for carers and patients • Role of GPs in initiating response and recognising problems • Tipping point **Theme 5: Effect of BPSD on pwd and carers** • Affects daily activities (kitchen work, money handling) • Impact on relationship • Carer home consideration • Grief • Seeking Coping skills (don't shout back) **Theme 6: Types of BPSD** • Aggression, withdrawal, apathy, agitation • Anxiety, schizophrenia, hallucinations, depression • BPSD as reaction to moving and handling pwd	Although there are many different codes in place for GPs diagnose dementia, but some appear to miss early recognition of BPSD. GPs need to have access to information about local community services which support pwd and their carers at the time of diagnosis and beyond. Carers report not getting enough support or information as a general criticism of the system. In this context, more information is needed about the use of post emdass services for carers, including different BME groups. Dementia support services need to be more available to improve coping with caring for pwd. In particular flexible respite arrangements may help carers to respond to BPSD which can change quickly. As another example, Admiral Nurses are valued by carers as a support. It is suggested that best care is provided through a triad relationship between carer, pwd and practitioner, which can be difficult to arrange and maintain unless there is continuity of care.

Table 7F: Main Themes - Carers Focus Group and Interviews (Findings based on 12 interviews with carers and one focus group n=7)

Theme 1: Effect of BPSD on Carer	Theme 4: Barriers to services	Summary
• Difficulties in coping,		

• Stress • Sleeping disturbances • Worry, fear, • giving up own life **Theme 2: Types of BPSD** • Passive behaviour • Aggression (Shouting) • Strange behaviour • Confusion • Partnership fades away • Increasing impact on relationship **Theme 3A: Support / Interventions** • Admiral nurse, Day centre, Respite, , Gardening & hobbies, • Counselling, CBT, improved communication skills (Don't argue back) **Theme 3B: Implications (help or support that would help** • Carers need to be supported • Day care needs to be tailored to needs of people with dementia • Easy access to someone who can provide guidance or information on dealing with BPSD • Education of carers needed to better cope with BPSD and dementia in general • Need for consistent point of contact for guidance	• Information / service to support carers is not always helpful. • Carer needs to initiate contact with services • Some Carer resistance to long term care • Emdass (early memory diagnosis and support services) service specific to some locations only • Feeling that nothing will help • Lack of knowledge about available services • Information where to go for information • Unsure which service • No follow up • GP unaware of services • Lack of information at time of diagnosis • Carer delaying help until breaking point • Denial **Theme 5: Recognition of BPSD** • GP may not be helpful • Some GPs were reported as having some difficulties in recognising BPSD (the may recognise and diagnose dementia in general)	Many carers experienced passivity in the person they support as a phenomenon that increases over time as the disease progresses. Caregivers may feel profound stress, sadness and grief associated with the deterioration and effect of passive behaviour. This is a major theme linking with types of BPSD and effect of BPSD on carers and pwd. Interventions for carers are important for managing BPSD and the challenges that come with it. Carers mentioned respite or getting help by Admiral nurses. However, it was pointed out that funding for Admiral nurses was uncertain even though the service was appreciated by carers. In addition GPs were considered to be unaware of services or the information does not cover coping with BPSD. Some carers would like enhancement of their skills through education and training as the most desirable intervention (1st phase interview)

Table 7G: Main Themes - People with Dementia Interviews (Findings based on 13 interviews with people with dementia)

Theme 1: Types of BPSD experienced by pwd	**Theme 3: Support / interventions**	**Short Summary**
• Anger, aggression	• Day centre, café	

• Strange behaviour • Giving up • Confusion • Denial • Apathy • Repetitive • Gradual decline ○ Can’t do things anymore ○ Effect on relationship ○ Other health problems • **Problems with daily activities (pwd)** ○ Dressing ○ Cooking ○ Sleeping ○ Going on Outings ○ Cleaning, Washing ○ **Theme 2: Effect of BPSD on carer** • Difficulty to cope • Triggers of BPSD-tipping point • Frustration, annoyance • Confusion • Anger • Loneliness • Denial • Sacrifice	• Community district nurse • Drama • Singing • Technology • Art gallery • Hobbies • Counselling • Religion **Theme 4: Barriers to services** • No service- service stopped • Service not useful • Don’t want service • No information • No follow up • Lack of information available about what to expect • Normalising behaviours or problems • Pwd denial of dementia or problems • **Theme 5: Recognition of BPSD** • GP not helpful • Difficulties recognising BPSD • Help needed with recognising BPSD • PWD does not recognise BPSD	Although pwd were interviewed, in 6/8 interviews the carer answered most of the questions as proxy in the presence of the patient. The major themes were difficulties with behaviours and emotions. Especially anger, aggression and strange behaviour exhibited by pwd impacted on the emotions of carers. They found it difficult to cope with aggression or were frustrated or annoyed by strange and embarrassing behaviour. Day centres, cafés or activity centres were found to be useful for carers supporting pwd. For example, a Singing group appeared to calm pwd down when agitated.

Table 7H: Main Themes - BME Groups (Findings based on five interviews of which three interviews were carer proxy reports of people with dementia and two carer interviews)

Theme 1: BPSD affecting carer	**Theme 3: Recognition of BPSD**	**Summary**

• Stress • Difficult to cope • Desperate • Giving up own life • Isolation • Worry, fear **Theme 2: Types of BPSD affecting pwd** • Aggression, grumpy, violent • Daily activities • Strange behaviour • Not talking • Shouting **Theme 2: Support / Interventions** • Dementia concern • Counselling • Paid help • Family help • Outreach worker	• Difficulties recognising BPSD • GP not helpful in giving information • GP not recognising BPSD • Seeking help from outside • Stigma • Misunderstanding of BPSD **Theme 4: Cultural issues** • Limited understanding of dementia by some people from Asian backgrounds • Dementia may be mistaken for old age • Communication problems **Theme 5: Barriers to services** • Info service not helpful • Service not available • don’t know which service • Don’t want service	Stress around coping and not being understood culturally. Accessible sources of support to suit their needs are required Carers had difficulties to cope with the stress and desperation that came along with caring for pwd. There seems to be limited understanding of dementia by some people from the Asian backgrounds. Here Dementia may be mistaken for old age. Some information that is available about managing dementia and BPSD appear not to be helpful for cultural and communication difficulties (language barrier). It appears from the comments that people with an BME background in the UK are sometimes stigmatised within their community.